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HOUSE OF REPRESENTATIVES

CONTINUING JEOPARDY: CHILDREN AND AIDS

A STAFF REPORT

OF THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

ONE HUNDREDTH CONGRESS

SECOND SESSION

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LETTER OF TRANSMITTAL

To: All Members Select Committee on Children, Youth, and Families:

I commend to your attention this staff report, "Continuing Jeopardy: Children and AIDS," that provides an update of the Select Committee's December 1987 report, "A Generation in Jeopardy: Children and AIDS."

The study highlights the continuing rapid growth in reported cases of AIDS (Acquired Immune Deficiency Syndrome) among children, the widening geographic spread of HIV infection among this population, and the progress made in addressing the problems since the issuance of the Committee's initial report.

The Committee will continue its efforts to monitor closely the circumstances of this highly vulnerable group of American children and their families and to seek timely and appropriate responses not only to ensure their humane treatment but also to stem the stream of children entering this population.

Sincerely,

GEORGE MILLER,
Chairman.

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CONTINUING JEOPARDY: CHILDREN AND AIDS

Introduction

At the end of 1987 the Select Committee on Children, Youth, and Families issued a report, "A Generation in Jeopardy: Children and AIDS," documenting the impact of the epidemic on the Nation's young children, adolescents and their families. Since that time, we have continued to observe the insidious sweep of HIV infection across the Nation and its escalating effects on the youngest and most vulnerable.

These critical issues have commanded the attention of a growing number of experts and advocates. There are more reports addressing HIV infection among children and youth (1); a new coalition of national health, education and child welfare agencies has formed to educate its memberships, policymakers and the public (2); and children and youth with AIDS or who test antibody positive are now at the very least a notable part of discussions among researchers, service providers and policymakers dealing with the HIV epidemic.

Congress has led efforts to increase funding for research and other AIDS related activities, and has begun to address critical treatment and care issues for HIV-infected children. Since the Select Committee's initial report, Congress has approved and is considering additional health and foster care legislation that will help states and communities serve infants and young children with or suspected of having HIV infection. The continuing urgent challenge to Congress is two-fold: to support the development of more humane and cost-effective treatment and care, and to stop the spread of HIV, thus preventing the stream of children from becoming infected and entering the systems of care in the first place.

This report presents a snapshot of the progress made and the distance yet to cover in addressing the magnitude of the epidemic and its unrelenting assault on children and their families. We have tracked the course of the epidemic among children and youth with the help of noted experts who have testified before the Committee in 1988 and other experts whom we have interviewed, and have reported trends based on surveillance data gathered by the Centers for Disease Control as well as reports issued during the last several months.

HIV Infection and AIDS Continue To Affect More Children in More Places; Largest Increases and Greatest Crises Facing Infants and Young Children

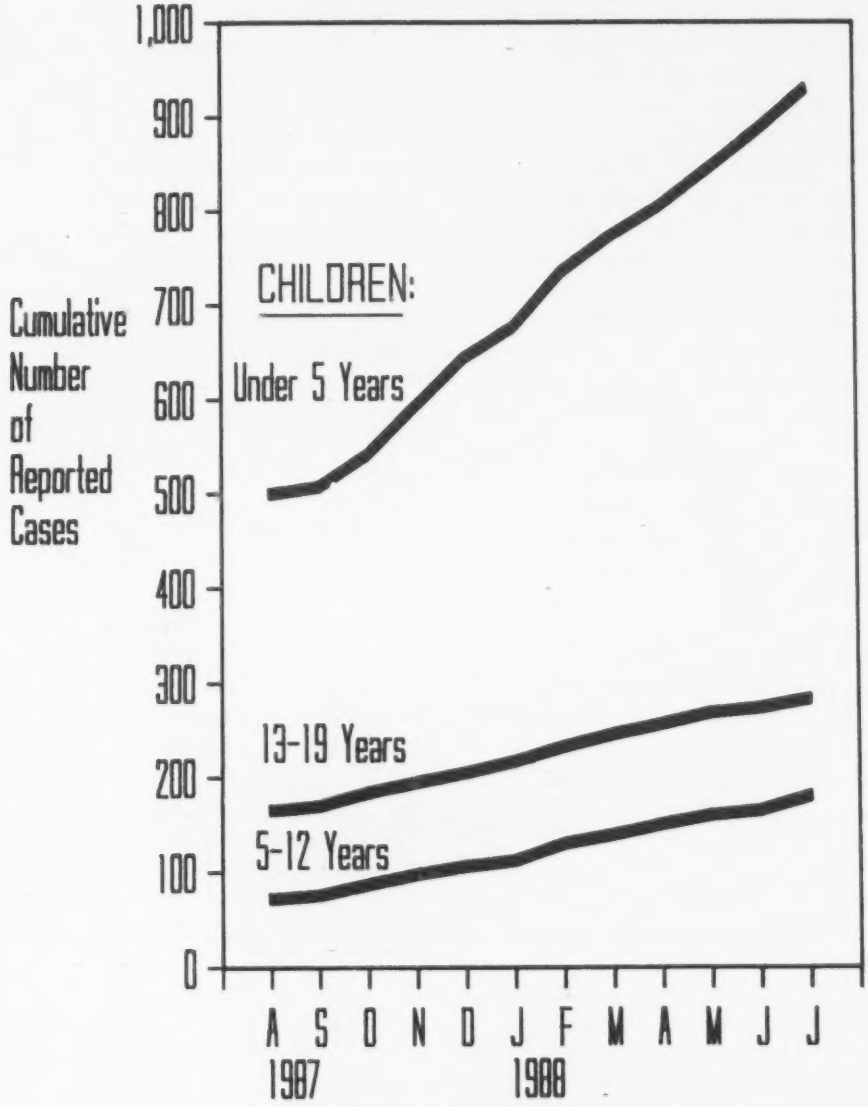
As of August 1, 1988, there were 1,108 reported cases of AIDS among children under 13, an increase of 48% from 750 cases at the end of the 1987. Reported cases among adolescents aged 13–19 to-

taled 283 at the beginning of August, an increase of approximately 80 cases since the end of 1987 and more than twice the number of cases reported among that age group at the time of the Select Committee's first hearing in February 1987 on the issue of AIDS and children. Children under age 5 have registered similar large increases in the number of reported cases, up 44% from 644 to 928 between the beginning of the year and August 1, 1988. [See Figure 1; (3)] Experts project 10,000 to 20,000 pediatric AIDS cases by 1991. (4)

FIGURE 1

REPORTED CASES OF AIDS AMONG CHILDREN AND YOUTH

AUGUST 1987 - JULY 1988



Source: CDC. AIDS Weekly Surveillance Report - United States. (Reports issued closest to end of month utilized.)

Although the numbers of reported cases among these populations are still relatively low, the rate of increase continues upward at a frightening pace.

Dr. James Oleske, a pioneer in working with infants and young children with HIV infection at Children's Hospital in Newark, New Jersey, told the Committee in July 1988 that sadly, but not unexpectedly, he continues to see an upswing in numbers, with most of the population born during 1987. He reported that the screening clinics affiliated with Newark's Children's Hospital see some 30–35 potentially new patients every two weeks. (5)

The geographic spread of reported cases also is widening. In February 1987, 33 states and territories reported cases of AIDS among children under 13; 40 were reporting at the end of 1987; and 44 were reporting at the beginning of August 1988. Nearly one-third of those jurisdictions reported 15 or more cases of pediatric AIDS, compared to 5 states in February 1987. The most affected areas continue to be New York, New Jersey, Florida and California, each reporting 75 or more cases at the beginning of August. Texas, Puerto Rico, Connecticut, Maryland, Illinois, Pennsylvania, Massachusetts and Georgia comprise a second cluster, with each of these states reporting more than 20 pediatric AIDS cases as of August 1, 1988. (6)

There are still few data on the incidence of new HIV infection that could allow better estimates of the spread and course of the epidemic. Generally, studies have shown a lower incidence of HIV infection among homosexual men in the last few years than in the early 1980s, and procedures to screen and safeguard the supply of blood and blood products have reduced new infections among hemophiliacs and transfusion recipients. In contrast, the incidence of infection is rising fast among populations of IV drug abusers. (7)

The vast majority of HIV-infected younger children (under age 13, and particularly under age 5) continue to become infected before or during birth by their mothers who used IV drugs or were the sexual partners of IV drug abusers. As of August 1, 1988, nearly 80% of the reported AIDS cases among children under 13 were attributed to transmission from a parent with or at risk of AIDS; 13% to contaminated blood transfusion; 6% to receipt of contaminated clotting factor for control of hemophilia; and 4% undetermined. (8)

Oleske also noted that over the past year, he has become "reimpressed with sexual abuse as a real and legitimate means of infection." (9) Out of 15 sexually abused preadolescents seen in his clinics, three were infected.

The epidemic also is continuing to ravage poor and minority children, their families and communities disproportionately. Many of these communities and their residents lack the resources and social supports to cope with the chronic and deadly effects of HIV infection. (10) As of August 1, 1988, more than 80% of the reported cases among children under 5, and about half of those 5–12 and 13–19 were among minority group children. The proportions have remained fairly steady since the end of 1987 when they were 82%, 52% and 51% respectively. (11)

Risks of HIV Infection Among Adolescents Increasingly Recognized, But Information on the Population Still Scarce

Among the "20 most important findings and recommendations" made by the Presidential Commission on the Human Immuno-deficiency Virus Epidemic, adolescents are highlighted as a separate, special target population and addressed as follows:

> The problems of teenagers, and especially runaway youth, that place them at increased risk for HIV exposure must be aggressively addressed. The spread of HIV within the heterosexual population should be better defined and accurate information communicated to the general public. Inaccurate and misleading statements suggesting that HIV cannot be spread through heterosexual activity are unwarranted. (12)

While there are no large scale studies on adolescents, regional and local studies in areas of highest HIV prevalence confirm rising numbers of youth with AIDS as well as the danger of infection among many youth who engage in risk behaviors. Analysis of the rates of reported AIDS cases for 13–21 year-olds shows that the number is doubling every year (13, 14). The Presidential Commission cited preliminary results from a Baltimore study showing that the prevalence of HIV infection in adolescents using Baltimore city health clinics is 1.5 to 2.0 percent (15). In New York City, program staff at Covenant House, an agency that provides shelter, counseling and other services to runaway youth, have reported rising numbers of young people who test antibody positive. (16)

Unfortunately, national AIDS surveillance data group adolescents with adults. The surveillance information does not provide separate data on reported cases among adolescents by state or SMSA (Standard Metropolitan Statistical Area) of residence, or by categories of transmission. Karen Hein, M.D., of the Department of Pediatrics at Albert Einstein College of Medicine in New York and expert on adolescents and HIV infection, has repeatedly told the Committee of the dearth of information on adolescents and the epidemic. This lack of information creates difficulties for both gauging the spread of HIV infection among this population and providing appropriate prevention and care. According to Hein, "we don't have a clue as to the natural course of HIV infection among adolescents, and we really need to look at that." (17)

A recent examination of adolescent AIDS cases in New York City by mode of transmission indicated that 44% were homosexual/bisexual males; 23% intravenous drug abusers; 11% female partners; 11% those infected by blood products; and 11% other. While the major modes of spread of HIV among adolescents are like that of adults—through sexual contact or by sharing needles with an infected person—there are differences in transmission patterns between adults and adolescents as well as between children and adolescents. Reported cases among adolescents show proportionately fewer attributable to homosexual/bisexual contact, more IV drug abuse, and much more heterosexual transmission. The drug abuse and sexual activity connection is underscored in a recent report from Covenant House indicating that of the 30 youths there who

tested positive in the last year, three-fourths said that they had engaged in sex related to their crack-cocaine habits. (18)

Hemophiliacs: While New Infection Unlikely, High Prevalence of HIV Among the Population Poses Continuing Serious Problems

According to the National Hemophilia Foundation, approximately 12,000 hemophiliacs have been infected with HIV, and 5% to 25% of their sexual partners test positive. As of July 25, 1988, 712 cases of AIDS were reported among hemophiliacs, with 59 cases among children under 13 and 88 cases among adolescents aged 13–19. (19) According to Louis Aledort, M.D., Professor and Vice Chairman of the Department of Medicine at the Mount Sinai School of Medicine in New York, HIV-infected hemophiliac patients still take a lot longer to progress from initial infection to symptomatic disease. He also reports, however, that we "haven't progressed very far" over the last year in addressing HIV infection among this population, and "don't have a good handle on" how to reach and educate especially young persons who are infected. (20)

Dorothy Hancock, a counselor with the Mt. Sinai program for hemophiliacs, told the Committee in July that the young people as well as their parents say that they cannot handle the situation. She has observed that although there are "no common patterns, how well families have dealt with hemophilia suggests how well they might deal with AIDS." (21) Practitioners who work with both HIV-infected hemophiliac adolescents as well as HIV-infected youth in the general population have also noted similarities between them in that individuals in both groups deny their status and in some cases, act out in ways dangerous to themselves and others.

Care of HIV-Infected Children Increasingly Challenges Health Care and Social Service Systems; More Humane and Cost-Effective Care Sought

The care of babies and young children exposed to HIV has attracted the most attention, public concern and formal action to date due to rapidly growing numbers and the increasing, complex and costly responsibilities for public health and welfare systems.

In some inner-city clinics, 4% to 5% of pregnant women are infected. (22) A study of births in New York City over 6 months revealed that one in every 77 babies born is seropositive. (23) Data from a recent assessment by the New York State Health Department indicated that in some parts of New York City one in 22 women who gave birth were infected. (24)

Many of these babies are medically fragile at birth because of drug exposure and/or HIV infection. Oleske reported to the Committee that the comprehensive case management approach employed in the program at Children's Hospital in Newark has "improved the quality of life and more importantly, its duration." Of the total 168 young patients seen, 40 have expired, a lower overall mortality than the national average. (25)

Some of these children may be able to leave the hospital, but because their parents are unable to care for them and few other ap-

propriate arrangements are available, these infants often spend a good measure of their lives in hospitals. Few alternatives to hospital-based care exist for the babies and young children who may not have a home to go to and who are difficult children to care for because of their known and suspected medical problems. Oleske reports that approximately 40% of the children he serves are under the care of the state through departments of child protective services.

The still small number of reported cases of AIDS among children—even among infants and young children who have the fastest growing rate—dramatically understates the problems presented by new cases of HIV infection which may not yet meet AIDS cases reporting definitions, and the problems of drug exposure that place many children at risk of HIV infection in the first place.

In the Select Committee's hearing on AIDS and young children in February 1987, Jean McIntosh, Assistant Director of the Department of Children's Services in Los Angeles County, reported that the numbers of requests for foster care for drug-exposed infants and toddlers increased about 1000% between 1981 and 1986 from 132 to 1,363 cases. (26) At the Committee's hearing in Los Angeles in April 1988, the Department's director, Robert Chaffee, reported that the number of these referrals rose to 1,916 in 1987. (27) At the same hearing, Xylina Bean, M.D., Director of the Intermediate Care Nursery and Infant Follow-up Programs at Martin Luther King Jr. General Hospital in Los Angeles, reported a nearly 100% increase at that hospital alone from 1985 to 1986 in the number of babies (more than 400) born having prenatal drug exposure. (28)

Non-hospital based care for these children is not only more humane but is increasingly shown to be much more cost efficient. The Committee's report on children and AIDS described several proposed and ongoing efforts to serve HIV-infected children in non-hospital based settings. In a hearing of the Select Committee this spring, the Committee also learned about the San Francisco Fragile Infant Program, which provides a specialized foster care setting with attendant health services for medically fragile infants. This program costs from $1682 to under $2000 per infant/per month in contrast to the Medicaid cost for an infant in a hospital of $6375. (29)

The Presidential Commission highlighted this imperative to identify and support more humane and cost-effective approaches:

> While hospitals and service agencies are stretched to their limits in some areas with a high incidence of pediatric HIV infection, other areas have yet to face the problem. While a serious problem now, care of an increasing number of HIV-infected children may overwhelm hospital budgets in the future unless a plan is developed to place these children in more appropriate settings, either with their own families or, where that is not possible, in a foster home or small group home. (30)

The Commission further highlighted the pressing needs of this population and the challenges facing their families and systems involved with their care in another of its major recommendations:

> The problem of HIV-infected "boarder babies" is one of the most heartrending the Commission has encountered. These children live their entire brief and tragic lives in hospital wards, with only doctors and nurses as family. The expected 10,000 to 20,000 HIV-infected births by 1991 also call attention to the critical need for foster homes. Unless the problems of the disadvantaged are addressed, the HIV epidemic will continue to make inroads into these populations and we will see large increases in both pediatric and drug-related HIV disease. (31)

In addition to these basic care concerns, a new issue related to the care of these HIV-infected babies has emerged since last year. In the last two months, Children's Hospital in Newark has begun AZT drug treatment with children. According to Oleske, the Division of Youth and Family Services in New Jersey has denied to the babies under its charge participation in clinical trials of AZT drug treatment, which holds promise for improving the span and quality of life of HIV-infected children. Oleske calls this a real problem saying the Division of Youth and Family Services "in the name of protecting children, really may be harming children." (32)

Need for Improved and Expanded Drug Abuse Prevention and Treatment Efforts Undeniable and Growing

Added to the devastation already wreaked by drug abuse, populations of drug abusers will show the largest increases in new HIV infection in the coming years and constitute "a major port of entry for the virus into the larger population" with a grave impact on women of childbearing age and young children. (33)

> Although intravenous drug abusers constitute only 25 percent of AIDS cases in the United States, 70 percent of all heterosexually transmitted cases in native-born citizens come from contact with this group. In addition, 70 percent of all perinatally transmitted AIDS cases are the children of those who abuse intravenous drugs or whose sexual partners abuse intravenous drugs.

Despite the present danger and growing threat, treatment reaches only about 12% of the estimated 1.2–1.3 million intravenous drug abusers in the Nation. The Commission concluded that "it is imperative to curb drug abuse, especially intravenous drug abuse, by means of treatment in order to slow the HIV epidemic," and recommended a national policy of providing "treatment on demand" for intravenous drug abusers. (34)

The Commission pointed further to the cost effectiveness of investing in prevention and treatment:

> Given the fact that temporarily alleviating the health effects of symptomatic HIV infection can cost as much as $100,000 per person and that imprisonment costs an average of $14,500 per person per year, . . . the investment necessary to provide for intravenous drug abuse "treatment on demand" is sound public policy. Current treatment modes for intravenous drug abusers, including methadone maintenance and drug-free residential communities,

> reduce illicit drug use, improve employment among addicts, reduce crime rates, and improve social functioning. (35)

Drug abuse alone is estimated to cost the Nation $60 billion annually in health care expenditures, law enforcement, related criminal activity and reduced productivity. (36)

The Institute of Medicine/National Academy of Sciences (IOM/NAS) also emphasized the need for expanded treatment and prevention in its recent report:

> The fear of AIDS will probably lead some IV drug users to seek treatment for their addictions. But in the United States as a whole, the availability of treatment for IV drug use was less than the demand even before the AIDS epidemic. Thus, a major possibility for reducing illicit IV drug use and the transmission of HIV is expansion of the system for treating IV drug use. Through treatment, users who have not been infected with HIV could greatly reduce their chances of being infected, and users who have already been infected would be less likely to infect others. At a purely economic level, treating AIDS costs from $50,000 to $150,000 per case, whereas drug abuse treatment costs as little as $3,000 per patient per year in nonresidential programs. (37)

Education To Prevent HIV Infection Increases, But Remains Insufficient

While the number of states mandating AIDS education in the schools has grown over the last several months, still only half have acted. In addition, little is known about what the mandates actually mean in educational practice in the various states. IOM/NAS also reported in its update that much of the activity has been fraught with controversy that impedes rather than fosters whatever educational effort exists.

At the end of 1987, the Committee reported that according to the National Association of State Boards of Education (NASBE), 18 states had mandated some AIDS education. As of the beginning of July, 25 states had state board of education or legislative mandates for AIDS education. NASBE plans to conduct another formal survey this fall. (38)

Although AIDS information is gaining broader distribution with more states mandating AIDS education and with activities such as the mailing of the AIDS information brochure from the U.S. Public Health Service to all American homes, questions regarding effectiveness of the information and the tough problems of getting individuals to change behavior remain unanswered. According to a new assessment of AIDS education by the Office of Technology Assessment, "although education on AIDS and sexuality appears to increase adolescent knowledge, there is little evidence that youth translate such knowledge into changes in their risk behaviors." (39)

Oleske recently commented that "It is not so much that we need to educate, but we need to motivate. . . . That's the hard part." He has emphasized that prevention cannot be limited to education and

behavior change alone. His experience in Newark has demonstrated that "AIDS is a disease of poverty and drug abuse, and until we address these larger issues, we won't really solve the problems of AIDS." (40)

Among its major recommendations, the Presidential Commission renewed the call for comprehensive and age appropriate education programs:

> Education programs must continue to be developed and implemented for the near term, and for the greatest possible impact on the next generation. Age appropriate, comprehensive health education programs in our nation's schools, in kindergarten through grade twelve, should be a national priority. (41)

The National Response: Still Too Little

In 1986 in its initial assessment and report, *Confronting AIDS,* IOM/NAS decried the national response and dedication of national resources to combat the HIV epidemic. (42)

In June 1988, while citing and commending progress in areas of biomedical research, broad-based education, ongoing Centers for Disease Control surveillance, and the extensive and impressive work of the Presidential Commission, IOM/NAS concluded again that the federal response remains too uneven with a continuing lack of coordinated federal policies and leadership. (43)

> The lack of guidance in federal policymaking is manifested by false starts and misguided efforts. . . . In the absence of strong federal leadership, a variety of private organizations, foundations, volunteer groups, professional organizations, and state and local governments have taken the initiative to create education programs, formulate laws and regulations, and address other facets of the epidemic. These efforts are an enormous contribution to the progress that has been made thus far against AIDS and HIV infection; nevertheless, the absence of coherent national direction condemns many localities to "reinvent the wheel" when it comes to setting local policy and increases the likelihood that failed experiments will be repeated from place to place. (p. 166)
>
> Where direction has been reasonable, the lack of forceful policymaking may have done little harm. But where public policy has been clearly inadequate—for instance, in the provision and financing of health care, in setting standards for antibody testing and antidiscrimination, in addressing IV substance abuse, and in furnishing overarching direction for all components of the government and the private sector—the nation has suffered from the absence of strong federal leadership. (p. 167)

The year-long Presidential Commission on the Human Immunodeficiency Virus Epidemic provided in 1987 and 1988 the most visible federal policymaking activity on HIV infection and AIDS. This effort was nearly undermined by disorganization and dissension in the first few months of its existence. Although never without con-

troversy, from the latter part of 1987 through the issuance of its final report, the Presidential Commission, under the chairmanship of retired Adm. James Watkins, succeeded in bringing to the public's attention the known facts about HIV infection and its impact, and in focusing efforts on what could and ought to be done.

The Commission concluded its work and issued its final report in June 1988. The recent work of IOM/NAS also called for significantly greater efforts in many of the same areas designated by the President's Commission and reaffirmed its earlier recommendation that a national commission on AIDS and HIV infection be established with a five-year renewable term. (44)

Early in August, President Reagan responded to the Commission's effort with a plan that has been criticized for failing to include many of the Commission's recommendations.

Congressional action continues to focus mainly on funding support for AIDS related programs principally under the Public Health Service. The House and Senate have agreed to FY 1989 appropriations of $1.2 billion for AIDS disease control and research activities.

Since the Select Committee's initial report, Congress approved as part of the 1987 Budget Reconciliation Act legislation authorizing demonstration programs to care for infants with or suspected of being HIV infected and abandoned in the care of hospitals, and a study of foster care for children with AIDS by the Department of Health and Human Services. During the last few months, legislation (H.R. 4843) to improve strategies to serve infants abandoned because of HIV infection or drug abuse has received action by the relevant committees in the House; in 1987, the Senate approved S. 945, a similar measure.

In addition to these actions, a provision of the new Medicare Catastrophic Coverage Act, allows states to develop special individualized services for these infants and young children that will be paid for under the Medicaid program.

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